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EXPERIENCES OF PREGNANT WOMEN DIAGNOSED WITH HIV/AIDS: A STUDY AT ACCRA METROPOLIS

BY:

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DECLARATION

DEDICATION

I dedicate this study to my husband Joseph Torku and my children Gloria, King and Michael

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ABBREVIATIONS

ANC	Antenatal Clinic
ART	Anti-Retroviral Therapy
CD4	Cell Cluster of Differentiation 4 White Blood Cell
CT	Counselling and Testing
DBS	Dry Blood Spot (blood taken from extremities of babies for HIVtesting).
EID	Early Infant Diagnosis
GAC	Ghana AIDS Commission
HTC	HIVTesting and Counselling.
JHS	Junior High School
MOH	Ministry of Health
MTCT	Mother-to-Child Transmission
PMTCT	Prevention of Mother-To-Child Transmission
SHS	Senior High School
UNAIDS	Joint United Nations Programme on HIV/AIDS.
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

ABSTRACT

Women who test positive for HIV during pregnancy continue to increase in Ghana. The experiences of pregnant women diagnosed with HIV during antenatal clinic visit were explored. The descriptive qualitative design was used to obtain narrative accounts on test experiences, coping strategies and availability of support for HIV positive pregnant women. Respondents were purposively selected from Ridge Hospital in Accra. Required data saturation was attained with a sample size of 10 respondents from in-depth interviews. The interviews were tape recorded and transcribed verbatim. Content analysis of the text data through a systematic classification process of coding and identifying themes and patterns was done concurrently. The major themes that emerged from the data were discovery and diagnosis of HIV in pregnant women, disclosure of status, attitude of midwives, experience of taking antiretroviral drugs, social support and coping strategies. Stigmatisation, rejection, lack of support and unfavourable experiences with midwives and other health professionals was prevalent during antenatal care and labour among pregnant women diagnosed with HIV. The women were unwilling to disclose their status because of the negative outcomes. It is imperative that prevention of mother-to-child transmission of HIV strategy place emphasis on psychosocial support for HIV positive pregnant women to enhance their quality of life.

CHAPTER 1

INTRODUCTION

1.0 Background

Acquired Immune Deficiency Syndrome (AIDS) is a disease caused by the Human Immunodeficiency Virus (HIV). A sub species of chimpanzees native to West Equatorial Africa have been identified as the original source of the virus that causes AIDS. Globally, it is estimated that the number of people living with HIV/AIDS in 2009 were 33.4 million; of whom 2.5 million were children younger than 15 years old. Sub-Saharan Africa bears the greatest burden with more than 68% of all persons infected with HIV/AIDS living in this part of the world (UNAIDS, 2009).

Studies have shown that women are more biologically and socio-culturally predisposed to the transmission of the HIV through sexual intercourse (UNAIDS 2008; WHO 2003). Women are biologically at twice the risk of HIV infection as men, but it is their relative lack of decision-making power, education, and economic independence that amplify their risk of exposure to HIV/AIDS (Israel & Kroeger, 2005). For this reason, they are often blamed for bringing the HIV infection home (Fredricksson & Kanabus, 2004). In low income countries such as Sub-Saharan Africa, HIV/AIDS is the major cause of death among women of reproductive age. Statistics show that in almost all the countries in sub-Saharan Africa, the majority of people living with HIV are women, especially girls and women aged 15 to 24 (UNAIDS, 2009). In Ghana, the peak ages for HIV/AIDS cases range from 25 to 34 for females - well within child bearing age (UNAIDS, 2011). This means that women within this age group who get pregnant are likely to transmit the infection to the infant if necessary intervention to detect and prevent the infection in this population is not taken. Mother to child transmission (MTCT) has been identified as the main cause of HIV infection in children and it is estimated that more than 600,000 children are infected with HIV each year, or 1700 a day(McIntyre, 2005). Up to half of the infections in children result from transmission through breastfeeding (WHO, 2004). As at 2009, the prevalence of HIV/AIDS among pregnant women worldwide was approximately 29.6% and 29% in urban and rural areas respectively (Quintal, 2010; UNAIDS, 2010; WHO, 2009). In Ghana, the prevalence rate among pregnant women attending antenatal clinics (ANC) was 2.9% in 2010; much higher than the national HIV prevalence rate of 1.8%. It is also estimated that the number of pregnant women diagnosed with HIV/AIDS in Ghana by 2010 was 13,000 (UNAIDS, 2011). Despite the increase in the prevalence of HIV in pregnant women, there is a paucity of information on the experiences of these women and their coping strategies.

It has been noted that the only effective way to enhance Prevention of Mother to Child Transmission (PMTCT) is by routine HIV counselling and testing (WHO, 2007). Ghana has adopted routine HIV Counselling and Testing for all pregnant women at the ANC all over the country; since PMTCT limits the proportion of new-borns infected with HIV/AIDS and improves maternal health and child survival (MOH/WHO, 2010). In the “National Guidelines for PMTCT”, the Ministry of Health (MOH) has outlined procedures for prevention of mother-to-child transmission (PMTCT) (2010). According to these guidelines, women who test negative after initial testing are expected to repeat the test in the 3rd trimester. A woman who tests positive with a CD4 counts less than 350 cell/mm3 is put on anti-retroviral treatment at 14 weeks of gestation. Infants exposed to HIV are also given Zidovudine daily for six weeks. An alternative of Neverapine is given daily where it is detected that the baby has any hemorrhagic disease or anaemia. This is to be complemented with improved obstetric practices such astimely Caesarean section, no artificial rupture of membranes, and administration of Anti-retroviral treatments during labour as well as avoidance of prolonged labour(MOH/WHO, 2010). These guidelines, though important in the fight against HIV/AIDS do not reflect what these women go through when diagnosed and put on treatment. To date, there was no evidence that suggested that the experiences of these women were integrated in drawing up the guidelines.

The magnitude of the importance that PMTCT programmes have in the HIV/AIDS prevention policies, has led to the implementation of policies and strategies for its expansion. UNAIDS(2001)indicated that women have suffered disproportionately from discrimination against people living with HIV/AIDS. The pandemic has led to gender-based violence as HIV positive women are assaulted, prevented from having children, dismissed from employment, disowned or shunned by their families and communities and sometimes even killed. There is every indication that gender-based discrimination, stigmatization and violence suffered by these women will increase. This is largely because PMTCT programmes engender situations where women are usually the first to know their HIV positive status before disclosing it to their partners or husbands.

1.1 Problem Statement

Pregnant women with HIV/AIDS need psychosocial support to enable them deal with all matters associated with their diagnosis and pregnancy. This includes Anti-Retroviral Therapy(ART), uncertainty about the safety of their unborn babies, disclosure and identifying coping strategies. Rosendo da Silva (2008), discovered that pregnant women with HIV suffer from a variety of emotional distresses; namely, anxiety, fear, loss, separation, prejudice, doubt and hope. It has been stated that the diagnosis of women as HIV positive results in serious psychological problems. The ability to cope with pregnancy and its outcome and functioning as parents tend to be negatively impacted by HIV/AIDS diagnosis (Blaney, 2004; Alder, 2004; Psaroset al., 2009). An increasing number of women get to know their HIV status during the antenatal period. There is need for psychosocial support and interventions that will enhance their quality of life during pregnancy, labour and the pueperium. Some studies have reported inadequate care and psychosocial support for mothers infected with HIV/AIDS (Amon, 2002; Skinner & Mfecane, 2004); especially for women with low income status who depend on men for their daily living. In addition, there is scarcity of literature on the psychosocial effects of being pregnant and diagnosed with HIV/AIDS (Sanders, 2008); this scarcity is more prominent in countries where the PMTCT programme was in theearly stages as in Ghana.

According to the PMTCT factsheet on Ghana, testing of pregnant women for HIV has increased steadily from 1% in 2004 to 51% in 2009. Although only 19% of ANC sites offer PMTCT services currently, the PMTCT programme in Ghana has set targets to expand PMTCT to 90% of all pregnant women with HIV by 2015 (UNCEF, 2011). This implies that more pregnant women will soon undergo HIV/AIDS testing as part of ante-natal care. Studies show that a lot more women are likely to test HIV positive during antenatal screening. Exploring the experience of HIV positive testing during pregnancy is important to managing the outcome of PMTCT of HIV in Ghana.

Some studies have reported experiences such as rejection, stigma and discrimination as common among persons living with HIV/AIDS (Johnson, 2002).The vast array of literature dedicated to the study of coping in HIV positive patients have overly concentrated on homosexuals and intravenous drug users since HIV was initially identified in these groups (Shisana & Zungu-Dirwayi, 2003; Sanders, 2008). The assumption that the findings from such studies can be applicable to other social groups is inaccurate, especially in the case of pregnant women with HIV, since these two classes of people experience different psychosocial burdens with HIV diagnosis. In Ghana, very little research exists on the experiences that pregnant women diagnosed of HIV/AIDS go through from day to day. Consequently, this research seeks to explore the experiences of pregnant women diagnosed with HIV/AIDSin order to appropriately support them.

1.2 Purpose of the Study

The purpose of this study was to explore the circumstances ofselected pregnant women diagnosed with HIV/AIDS in the PMTCT programme in the Accra Metropolis. It is also to provide information that could help in the establishment of social and medical structures to mitigate the negative effects experienced by pregnant women diagnosed with HIV/AIDS.

1.3 Main Objective

The main objective of this study is to examine the experiences of selected pregnant women diagnosed with HIV/AIDS. On the basis of information collected and the findings of the analysis of the date, problems faced by these women will be highlighted in order to draw attention to them.

1.4 Specific Objectives

The specific objectives of this study were:

1. To explore the emotional experiences of pregnant women diagnosed of HIV-AIDS
2. To identify psychosocial needs of pregnant women diagnosed with HIV/AIDS
3. To identify the support systems available to pregnant women diagnosed of HIV-AIDS

1.5 Significance of the Study

The study will highlight the challenges of pregnant women diagnosed of HIV/AIDS.The study will also equip the health care personnel with information on the psychosocial needs of pregnant women diagnosed of HIV/AIDS.

The findings are expected to inform healthcare policy makers to make policies which favour pregnant women diagnosed with HIV/AIDS.The study will add to the existing knowledge on HIV/AIDS and prevention of mother to child transmission in Ghana.

1.6 Operational Definitions

- Experiences: Any outcomes arising from being diagnosed with HIV/AIDS.
- Pregnant women:Any woman carrying a foetus in the uterus.
- Counselling: Providing guidance to enable the individual make an informed decision under the circumstance.
- Support: Lending a form of help whether physical, material or psychological to a pregnant woman diagnosed of HIV/AIDS
- Coping strategies:Ability to adapt and adjust to an existing situation.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

This section presents a review of relevant literature based on research work by other researchers. Key Words such as“HIV/AIDS”, “Pregnant women”“HIV positive Mothers” “Psychosocial Support”“Experiences”and “Coping strategies”were used to conduct the search. The review examined HIV/AIDS in Ghana, gender differences in HIV/AIDS, pregnancy and HIV, issues of stigma and discrimination, coping strategies of persons diagnosed with HIV and the forms of support available to persons living with HIV/AIDS

2.1 Gender Differences in HIV/AIDS

Women have been found to be more vulnerable to HIV/AIDS compared to men due to differences in biological, socio-cultural and economic factors that affect them (WHO, 2003). In 2002 alone worldwide figures showed that of all reported cases of newly infected adults, half were women (WHO, 2003). Though men are also infected with HIV with almost equal proportion, women are often blamed due partly to the fact that their HIV/AIDS status are known during prenatal testing (WHO, 2001).

Studies have shown that women’s vulnerability to HIV and AIDS is due to their biological disadvantage. Women are therefore twice as likely as men to be infected by HIV and AIDS from an infected partner during unprotected heterosexual intercourse (UNAIDS, 2008). Women’s vulnerability to HIV/AIDS can also be attributed to socio-cultural factors.

2.2 Pregnant Women and HIV/AIDS

As at 2009, the prevalence of HIV/AIDS among pregnant women worldwide was approximately 29.6% and 29% in urban and rural areas respectively (Quintal, 2010; UNAIDS, 2010; WHO, 2009). While being pregnant demands some life adjustments to be made, other demands are added for a woman who is pregnant and HIV positive. In addition to worrying about the unborn child's well-being and future, HIV positive pregnant women often have to think about the chances of transmitting the HIV virus to the baby when caring for the child.

2.3 Disclosure of HIV/AIDS Positive Status

Difficulty associated with disclosing or telling other people of one's HIV/AIDS positive status has been reported by researchers (Gebrekristoset al., 2004). Several studies have found disclosure rates to be generally low though there are significant variations. A review of 17 studies in 15 African countries revealed significantly low rates of disclosure of HIV positive status. In particular, it was reported that disclosure of HIV diagnosis 2 weeks to 4 years ranged from 16.7% to 86% (Medleyet al., 2004). Similarly, studies in South Africa involving 55 women in a rural community found that only 36% of them had disclosed their status 5 months after diagnosis (Sethosa & Peltzer, 2005).

Disclosure of HIV/AIDS status is a critical decision everyone diagnosed with HIV-AIDS is confronted with. Several factors have been documented as hindrances to disclosure of one's status. Specifically, fear of accusation of infidelity, rejection, discrimination, stigmatization, violence and abandonment and loss of partner support especially financial have all been reported as factors influencing perceived non-disclosure of HIV positive status by women (Medleyet al., 2001; Mamanet al., 2009). However,positive relationships built on trust and love bring about an increased likelihood of disclosure of one's status more than relationships characterized by lack of trust, multiple sexual partners and lack of love (Sigxasheet al., 2001; Antelmanet al., 2001).

Stigmatization and discrimination have been reported as major hindrances to nondisclosure. For instance, in a study involving men and women, it was observed that stigma and fear of discrimination significantly affected disclosure of HIV positive status. Thus, individuals were willing to disclose their status when they perceived low stigma and discrimination than when the likelihood of stigmatization and discrimination was high (Chandra, Deepthivarma & Manjula, 2003). Stigmatization has been found to lead to a number of negative consequences in people diagnosed with HIV/AIDS (Bauman et al., 1997). Decreasing rates of disclosure of HIV/AIDS status has been reported in a longitudinal study carried out in South Africa. In a longitudinal study to determine factors affecting disclosure among South African HIV-positive pregnant women, the researchers recruited 438 pregnant women attending antenatal clinics in Pretoria. Sixty two percent (n=293) of HIV positive women were enrolled from June 2003 to December 2004 and their socio-demographic and psychological factors were assessed using a questionnaire during pregnancy and 3 months after delivery. It was observed that at enrolment, 59% had disclosed their status to their partners and 42% had also disclosed to others. Follow-up revealed a rise in disclosure rates to partners (67%) and to others (59%). Logistic regression analysis also revealed a significant association between being married, prior discussion about testing, having a partner with tertiary education and less experience of violence and disclosure of HIV/AIDS positive status (Makinet al., 2008).

2.4 The Psychological Consequences of HIV Positive Diagnosis

Brandt (2005) conducted a study to investigate psychological experiences of HIV positive mothers in South Africa. The study was a qualitative study using semi-structured interviews. Five women with HIV positive were used. The findings were that women madea deliberate decision not to disclose their status in order to protect their important social network. The women also expressed their fears of dying before their children could be old enough to care for themselves.

Though the study made an important revelation about the fears of the HIV positive mothers, it could not be generalized because the sample size was too small. Studies conducted by Freeman, 2004, and Rosendo da Silvaet al., 2008 in South Africa noted women had strong need to maintain their role as mothers despite the difficult situation they find themselves in.

2.5 Discrimination and Stigmatization

Stigma is a barrier to effective social and medical care, it disrupts the benefits of antiretroviral therapy. Stigma includes prejudice which can lead to discrimination towards perceived or people actually infected with the disease, and can be a problem for people or institutions that harbour stigmatized individuals. Campbell et al., (2007) define discrimination as a negative behaviour while stigmatization is any negative thought, feeling or actions towards People living with HIV/AIDS. The difference between stigmatization and discrimination is while discrimination has to be acted out covertly; stigmatization can be overt (Gilmore & Sommerville, 1994).

According to Alonzo and Reynolds (1995), stigma is a construction of deviation from some ideal or expectation. Stigma represents a powerful discrediting and tainting social label which can change the individual's view of themselves and how others view them. Using a scale, Alonzo and Reynolds were able to categorize stigma into four distinct stages:

1. At risk: pre-stigma and the worrying state;
2. Diagnosis: confronting an altered identity;
3. Latent: living between illness and health; and

4. Manifest: passage to social and physical death (Alonzo and Reynolds, 1995).

Gilmore and Somerville (1994) also conceptualized four different stages of stigmatization in sexually transmitted diseases.These stages, they argued, covers at least four processes any stigmatisation response takes. First, is the problem – which can be described as the discredited attribute (Goffman, 1963), which can also be described as distinguishing and labelling (Link& Phelan, 2001). The second stage is identifying the People living with HIV/AIDS for targeted discrimination; it means the discriminated person must be recognizable in the society with some identifiable characteristics which can be used to label them correctly or erroneously. The third stage has to do with the target person who is labelled with the stigma. The target person is perceived as immoral and blamed for their predicament. The fourth stage has to do with the response of the stigmatized person. Here the person may be distanced, disempowered or controlled by the stigmatizer.

Koku (2010) found out that women diagnosed with HIV have been able to confront and resist stigma associated with their conditions in different ways. In his study, these women reported they kept their conditions secret, and were selective in disclosing confidential medical issues to their friends and family. Those who were bold enough to disclose their status did so out of the will to challenge public stigma and live normal lives.

Caldwell et al. (1993) using a case study approach reported that women also try to keep their status hidden from their spouses, friends and family to avoid stigmatization. These women go to various lengths to hide their status by attributing HIV-related illnesses to less stigmatizing ones. Some use heavy makeup, and clothing to hide some obvious bodily changes associated with antiretroviral drugs. These women's actions can be seen as bold attempts by People living with HIV-AIDS to control the powerful stigmatizing force that comes when their status is known in the community.

2.6 Depression

Depression is one psychological disorder that is frequently reported among People living with HIV-AIDS and other chronic diseases.Evidence linking depression with mortality in HIV positive individuals is very strong. Depression complicates the illness in HIV positive individuals. Research and clinical analysis have both suggested that recognizing and treating depression is vital to the prevention of morbidity and mortality in HIV positive individuals (Benton, 2008).

Morrison et al. (2002) compared 93 HIV positive women with 62 demographically matched controls and found a much higher prevalence for depression in HIV positive women (19.4%) compared to HIV negative controls (4.8%). In another study, Komitiet al. (2003) investigated the rate of depressive disorder and factors associated with it in patients with HIV/AIDS attending general practice. Using 322 participants with HIV/AIDS, the researchers found 22% of the sample who had met the criteria for the diagnosis of major depressive disorder. Variables that were associated with depression were support from family and past lifestyles such as drug use. While drug use correlated positively with depression, participants in a current relationship (social support) reported lower levels of depression. The study however did not find any correlation between HIV medical related variables such as use of ART and depression.

More recent studies have however found that an association between depression and HIV progression is not without the mediation of behavioural mechanisms such as substance abuse and non-adherence (Gore-Felton & Koopman, 2008). In a review, Gore-Felton and Koopman (2008) found that these behavioural mechanisms mediate psychosocial variables (such as stress, depression, coping and social support) and disease progression in HIV. Taken together it is imperative to tackle issues that promote these psychosocial factors as they have the tendency of impacting directly on the progression of HIV/AIDS.

Miles et al. (2007) studied the factors associated with emotional distress in 109 African American women with HIV. The relationship between factors such as social conflict, social support and spirituality and health-related factors such as perception of health, and cognitive responses like stigma on depression was examined. Their results showed that, younger age, more conflict, less social support, lower perception of health, and more HIV worry were associated with depression. Personal variables were the highest among all categories that determined the rate of depression of the People living with HIV/AIDS.

Depression affects disease progression by undermining the adherence to treatment plan. According to studies reviewed by Gore-Felton and Koopman (2008), there is a strong correlation between depression and HIV treatment adherence. Even when treatment adherence was controlled for, it was found that depression still affects People living with HIV-AIDS.

2.7 Social Support and HIV/AIDS

Most HIV and AIDS patients lack support: psychological, emotional and social support. In particular, pregnant women diagnosed with HIV are denied support of all forms. However, receiving the proper support in the form of friendship, family and professional support from health care professionals helps to lessen the burden of being HIV positive. Furthermore, being in a supportive environment can help alter the negative attitude the individual might have about themselves, which could lead to integrating with society and seeking help from others (Turner-Cobb et al., 2002).

Social support can greatly lead to positive coping behaviour because when HIV positive pregnant mothers are satisfied with support from families, friends, health professionals, spouses and significant others, they are more likely to have a positive mental state and therefore live longer than their counterparts who lacked support (Moskowitz, 2003). However, HIV positive pregnant women do not get the required support from health professionals, families and friends. They are rather stigmatized, rejected and discriminated against, so for fear of stigmatization and discrimination, most HIV positive women do not disclose their status.

2.8 Disclosure

Visser et al., (2008) conducted a study to determine the implications of disclosure of HIV status during pregnancy among South African women. They found that, the majority of women disclosed their status to their partners, family members and friends primarily because they wanted to gain support from them. The findings indicate that, the availability and provision of social support has enormous benefits in the fight against HIV and AIDS. According to Mdlalose (2006), disclosure of HIV status among pregnant women enhances access to social support and relieves them of the real burden of being HIV positive. Living in silence with the disease freezes the sources of support for pregnant mothers and the unborn baby. Further, Levy and Storeng (2007) in a study examined the narrative strategies of women living with HIV in Cape Town, South Africa. They observed that, participants stressed the importance of disclosure of their HIV status in dispelling the negative stereotypes and stigma associated with the disease and living with HIV. Though disclosure of HIV positive status is important, the will power to disclose or not to disclose is affected by the support climate. If HIV positive pregnant women perceive a positive social support network, they are more likely to feel comfortable disclosing their status than not disclosing.

2.9 Coping with HIV Positive Diagnosis

Coping strategies are diverse and most importantly must be selected carefully for the circumstance and time frame. Passive coping strategies like denial are associated with disease progression in HIV/AIDS. Such coping strategies do not help HIV positive individuals acquire any good behaviour for adaptive care. Unlike passive coping, active coping reduces disease progression in HIV positive persons because such strategies enable the People living with HIV/AIDS to develop behaviours that increase adherence to ART (Ironson et al., 1994). The consequences of coping strategies can be complex as well. It is likely that the coping strategies that are beneficial at the onset of the disease may become unnecessary and even harmful as the disease progresses, requiring different psychological resources to activate different resources. For people with HIV whose condition have progressed and need regular medical monitoring, the psychological process of being aware of one's psychosocial needs may be enough in activating adherence to medication (Gore-Felton & Koopman, 2008).

2.10 Religion as a Coping Strategy

Maman et al. (2009) studied 40 HIV positive women between the ages of 20 and 42 who were pregnant or had given birth within the last 12 months to find out how they used religion as a coping strategy. They defined spirituality as prayer, meditation, having faith in God and drawing one's strength from one's beliefs. Women receive a lot of support from their religious beliefs, associations and leaders; these set of different support types create a coping strategy for the women throughout their diagnosis, delivery and life in general.

The findings from their study showed that, when confronted with news of their HIV positive diagnosis, women found solace in their faith, using their church leaders and members as sources of support. These women also shared their diagnosis with others of the same faith, which became a long term strategy for coping with their condition.

Even though religion has been found to positively correlate with lower emotional problems in People living with HIV/AIDS (Sowell et al., 2000), these results obtained by Maman and colleagues cannot go without criticism. First, the interviews used in the survey were not designed to explore the depth of spirituality the women claimed. The interviews did not cover the manner in which they used their faith in solving their problems. It is believed that women diagnosed with HIV used many different coping strategies when they turn to their faith as a form of support. Some find solace only in the spiritual books of their faith, whereas others are able to better cope when they share their problems with people of the same faith.Secondly, the women interviewed were not asked to speak about their specific religious affiliations; this could have altered some conclusions and perhaps improved the overall generalizability of their research.

Kraukuer and Newbery (1997) reported that People living with HIV/AIDS who attend different churches had differences in their specific use of coping strategies because churches have different acceptance and tolerance for the People living with HIV/AIDS. Religion does not only help during the challenging stage of the disease, when individuals are initially diagnosed. According to Braxton et al. (2007), spirituality strongly and positively correlates with the feeling that life had improved. They used a hierarchical multiple regression to determine the association between spirituality and depression among 308 HIV positive black American women in the US attendingHIV/AIDS clinics. Spirituality was found to account for small yet significant proportion of variance in reducing depressive symptoms, well above other psychosocial factors. Their results suggest that spirituality plays an important role in enhancing the psychological adjustment of women living with HIV.

Studies carried out in Africa have overly focused on the role of religious associations on the coping strategies used by People living with HIV/AIDS. Religious groups and denominations have their own counter intuitive conservative approach to HIV prevention. In some jurisdictions, the use of condoms is prohibited which creates a conflict between the religious set up on one hand and the secular health authorities on the other (Takyi, 2001; Maman et al., 2009).These conflicts have dire consequences for the People living with HIV/AIDS. In one important case in Uganda, Wanyama et al. (2007) found out that 1.2% of

558 individuals on ARTdiscontinued treatment as a result of their faith, which they believed had healed them. The practice of discontinuing the use of ARVs due to pressure from religious beliefs could further endanger the health and survival of women living with HIV/AIDSand the transmission of the HIV infection to the yet to be born child.

2.11 HIV/AIDS in Ghana

The peak ages for AIDS cases are 25 to 34 for females and 30 to 39 for males in Ghana. Women's vulnerability to HIV/AIDS in Ghana and sub-Saharan Africa is not attributable solely to women'sphysiological susceptibility to heterosexual relationship but to socio-cultural, legal and economic challenges which confront women (UNAIDS 2007; Mwini-Nyaledzigbor, 2011).The prevalence of HIV among females is 2.7% and the empirical data in Ghana showed that the number of HIV/AIDS persons rose to 267,069 in 2009 with more than half (i.e. 154,612 persons) being women. In 2010, the number rose to 272,780 with a corresponding increase of 157,860 being women and 14,419 newly infected females (MOH/WHO, 2010). Though the prevalence rate of HIV/AIDS as well as number of women being infected keeps increasing, these statistics are not exhaustive as the data is likely to suffer from measurement errors and under reporting. This is because majority of the people are reluctant to test, therefore there could be so many people living with the disease but do not know their status (Mwini-Nyaledzigbor, 2011).

According to Mwini-Nyaledzigbor and Wright (2011), the increase in HIV infection among women in Ghana could be attributed to varied socio-cultural practices. The assertion made by these researchers was confirmed by Quan-Baffour (2007). Quan-Baffour (2007) points out that, stereotypes in most African communities is that every societal disaster ranging from failure in marriages, disease and deaths are caused by women. It is therefore not surprising that women are often blamed as responsible for their HIV positive status.

According to Mill (2003) there is an important link between promiscuity, prostitution and HIV infection. In line with this, women diagnosed with HIV/AIDS are often ignored and neglected in the Ghanaian communities once the person's HIV positive status is known (McGrath et al., 2003).

2.12 Summary and Conclusions drawn from Review

The issues studied in the majority of works cited above tended to focus generally on the causes, the prevalence rate, the consequences, or the coping strategies of HIV Positive patients. There has been little attempt by previous researchers to focus on women and in particular pregnant women diagnosed with HIV/AIDS.Some of the studies reviewed indicated that womendiagnosed with HIV had been able to confront and resist the stigma associated with the conditions in different ways.However, only a few studies were found on the experiences ofpregnant women diagnosed with HIV/AIDS.The motivation to undertake this research was therefore drawn from the apparent lack of emphasis on the impact of disclosure on pregnant women diagnosed withHIV/AIDS.

This study explores accounts of pregnant women who are HIV positive; the main question asked was when they became aware of their status and the aftermath of disclosure of their status.

CHAPTER 3

RESEARCH METHODOLOGY

3.0 Introduction

This chapter presents a summary of the research process used in obtaining, organizing and analysing data on the experiences of pregnant women diagnosed with HIV/AIDS in the Accra metropolis. It describes the research design, research setting, sample characteristics, data collection procedures and the data analysis process. The ethical procedures and methodological rigour are also explained.

3.1 Research Design

Descriptive qualitative design was used in this study to investigate the experiences of pregnant women diagnosed with HIV. The challenges that accompany their diagnosis, disclosure of status, reaction to HIV positive status and the strategies used to cope with their situation were elicited through in-depth interviews. The interviews were tape recorded and transcribed verbatim. Content analysis which involved subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes and patterns (Hsieh &Shannon, 2005) was done concurrently.

Qualitative research examines life experiences, in an effort to understand and give them meaning (Bryne, 2001). It also enhances interpretation and meaning of the participant's verbal report by enabling others to have a deeper understanding of the respondent's world (Basavantheappa, 2007). It is however necessary to establish that although qualitative research allows higher flexibility and presents more realistic view of the respondent's world; using a qualitative research method has some weaknesses such as problems of reliability which could be caused by extreme subjectivity of the researcher.

3.2 Research Setting

The Accra Metropolis is made up Okaikoi, Ashiedu Keteke, Ayawaso, Kpeshie, Osu-Klotey and Ablekuma sub metros. The Accra metropolis forms part of the Greater Accra Region. The Greater Accra Region, with a population of approximately 3,909,764 out of which 2,025,637 are female. The population density is 1,205 people per square kilometre and is home to 16.1% of the total population of Ghana (Ghana Statistical Service, 2011).There are several public and private health facilities within the metropolis however Ridge hospital was selected for the study because it is the regional Hospital.

Ridge Hospital was built in 1912 by an European Mining Company, it was after independence in 1957 that Dr Nkrumah turned it into a women's hospital that specialized in obstetrics and gynaecological cases. Less than twenty years afterwards, Col. Ignatius Kutu Acheampong, then military Head of State of Ghana, converted the hospital into a district hospital in 1974 to ease the pressure on Korle – Bu Teaching Hospital.

In 1996, Ridge became a Regional Hospital for the Greater Accra Region.The hospital occupies a total land area of about 15.65 acres. It falls within the district of Accra Metro and the Osu-Klottey sub metro district. The hospital renders services in areas of medical and surgical care, nutrition, Anti-retroviral Treatment (ART) and Preventing-Mother-To-Child-Transmission of HIV/AIDS (PMTCT) and Tuberculosis clinics. The hospital also offers Dental Care, Ear, Nose and Throat care; Radiology, Dermatology, Neurosurgical services, as well as, special services such as internal medicine, obstetrics and gynaecology, paediatrics and clinical psychology. It also has aNurse Anaesthetics school, situated at the hospital premises. The catchment area of Ridge Hospital is the whole of Greater Accra Region, but its immediate catchment areas include Nima, Maamobi, Kanda, Accra Newtown, Kotobabi, Osu, La, Adabraka and Achimota which are all suburbs in Accra.

Ridge hospital has been chosen for this study because it has a well-established Anti-Retroviral Therapy Clinic (ART clinic). It serves as the second major referral point for HIV positive persons and people with other ailments within Accra and beyond. The ART clinic is situated at the ground floor of the obstetrics and gynaecological unit of the hospital.The ART clinic is close to the family planning unit and cervical screening centre. It had a total HIV population of three hundred people at the time of this study.

3.3 Target Population

The target population was pregnant women diagnosed with HIV/AIDS through counselling and testing for pregnant mothers within the Accra metropolis. Participants were required to be within child bearing age and the age boundary was set at 15-45 years in order to accommodate all women in the reproductive age.

3.4 Sample Size and Sampling Technique

The researcher purposively identified pregnant women who tested positive during screening for HIV as part of the prevention of mother-to-child transmission strategy. The information sheet was used to explain the purpose and process of the study to potential respondents. Respondents who were willing to participate were then conveniently scheduled for interview at a date and venue of their choice.

The criteria for inclusion in this study were that the pregnant woman must be:aged between 15 to 45 years diagnosed with HIV/AIDS after pregnancy or during ante-Natal Care, antenatal clinic attendance at the Ridge hospital, able to speak Twi, English and Ewe and willingness to be recruited as respondent. Out of twenty (22) potential respondents contactedfifteen (15) were willing to participate in the study but five (5) were excluded because they did not meet the inclusion criteria, that is being able to speak English, Twi or Ewe which were the languages in which the researcher could communicate fluently with the respondents. A sample size of ten (10) pregnant women diagnosed with HIV/AIDS yielded the required data saturation level.

In qualitative studies the sample size is determined by data saturation which means that new themes no longer emerge from text data that is being coded even if interview is continued.

3.5 Tool for Data Collection

The tool for data collection was a semi-structured interview guide (Appendix C) that was used to obtain information on the experiences of the HIV positive pregnant women. Information was gathered on the demographic characteristics which included age, marital status, educational background and gestation period of pregnancy. The questionguide on their experiences was mainly open-ended with probing questions. Respondents were asked questions about their experiences as pregnant women living with HIV/AIDS; their experiences during HIV counselling and testing; the existence of stigmatization and discrimination against HIV positive pregnant women; the psychological and emotional reactions; extent to which activities of daily living had been affected and lifestyle in general.

The researcher who is a Nurse Midwife carried out the data collection. The observations made during the interviews were recorded in a field diary. Notes were taken during the interviews and a tape recorder was also used to capture the data gathered using the interview guide.

3.6 Data Collection Strategy

Qualitative research method facilitates researching people in their natural setting (Polit& Beck, 2008); hence people were identified at the regional hospital and traced to their homes where the interviews were conducted. After participants had been identified at the clinic, directions and addresses were collected from them and a date, time and venue of the interviews were fixed in consultation with the participants. However, a private room was made available by the hospital authorities for the participants who preferred to be interviewed in the hospital.

Informed consent was obtained from participants before commencement of the interview. The interview guide was used to conduct the interviews while using an audio tape recorder with the permission of the participants. Each participant was interviewed within 45 minutes and an hour. In addition, the researcher recorded the expressions and feelings of each interviewee in a field diary. The notes in the field diary were used to add meaning to the contents.

3.7 Data Management

The Researcher obtained data through direct contact and interviews of the respondents. The data was collected both on audio tape as well as hand written in the field diary. After which the interviews were transcribed verbatim and typed using Microsoft word. During typing the tape recorder was re-played to confirm the typed transcripts and any errors or omissions were corrected.

The respondents were classified and coded in a chronological order using upper case alphabets from A to J. A file was created for each respondent and the entire batch was put in a folder properly labelled for easy identification. The data was also saved on a hard drive of the personal computer as well as two separate pen drives. This was to ensure adequate data back-up for ease of replacement in the event of a loss or damage to any file or entire folder. Each file had a password to restrict unauthorised access to the file.

3.8 Data Analysis

Unlike quantitative data, qualitative data tends to be mixed with a level of bias from both the researcher and respondents. In analysing the data for this study therefore, the researcher was careful to reduce if not eliminate as much bias and prejudice from the information gathered as well as the deductions made there from. To achieve this objective, the tapes were transcribed and rechecked to ensure the researcher has clearly isolated the themes and sub-themes in the responses.

The responses were classified accordingly into the main themes and subsequently into the sub-themes. Microsoft word was used to generate a list of all the data responses each of which was referenced to the particular code of each respondent. This formed the basis of the quotes which were copied and posted to each theme and sub-theme in the study.

The researcher also relied on her field notes and diaries in the analysis of the data obtained. The unit of analysis was the interview text about experiences of pregnant women with HIV in the Accra metropolis. Concurrent data collection and analysis was done using content analysis with emphasis on both the latent and manifest content.

3.9 Data Saturation

Saturation in qualitative study begins with the recruitment of the participants and analysis of textdata by coding, categorizing and generating themes that continue until no additional themes emerge from the data. This means that interviews should be stopped because data would yield redundant information.

Table 1. Evidence of Data Saturation

Interviews	Evidence of Saturation
Interviews conducted	10
Interviews with emerging categories	8

Table 2. Major Themes and Sub-Themes

	Major theme	Sub-themes
1.	Discovery and diagnosis of HIV in pregnant women	• Routine counselling and testing • Reaction to HIV diagnosis • Perception of HIV counselling and testing.
2.	Disclosure of HIV positive status	• Disclosure to partner • Disclosure to family • Disclosure to significant others • Breach of trust.
3.	Attitude of health professionals	• Prejudice • Breach of trust and confidentiality • Stigma and discrimination • In-human treatment
4.	Experiences of HIV positive pregnant women on ARV	• Hiding to take the drugs • Long waiting hours • Inadequate funds for transport to the ART centre • Adherence to ARV treatment because of baby
5.	Social support for HIV pregnant women	• Family support • Partner support • Financial burden • Support from midwives • Social support group • Self support
6.	Coping strategies	• Prayer • ARV drugs

3.10 Methodological Rigour

To ensure rigour the study had a pre-test phase to test applicability of the research questions in drawing out the experiences of participants. Two participants had the interview guide tested on them but the data collected was not used in the main study findings.

3.11 Transferability

Transferability refers to the probability that the study findings will be of value to others in similar situations. Transferability is also called “fittingness”, for it determines whether the findings fit in or are transferable to similar situations (Streubertet al., 2003). It must be noted however that it is the potential user, not the researcher, who determines whether or not the findings are transferable. It refers to the extent to which findings from the data can be transferred to other settings. To ensure and facilitate transferability in this study, a clear and distinct description of setting and context, the selection and characteristics of participants, data collection and process of analysis have been outlined. A rich and vigorous presentation of ideas, together with the use of appropriate quotations, has also been used in the presentation of findings to enhance transferability.

3.12 Dependability

Dependability is another criterion used to measure trustworthiness in qualitative research. Dependability is met through securing credibility of the findings (Streubertet al., 2003). Dependability is dependent on the stability of data over time and is obtained with stepwise duplication and inquiry audit (Polit&Hungler, 2004).

In order to ensure dependability of the research study, a detailed description of research process has been done, and two supervisors re-examined the complete research process. Audit trail was also used as a way of ensuring dependability. In audit trial, the phases of research process were audited by the researcher under the supervision of two supervisors.

3.13 Conformability

Conformability is a neutral criterion for measuring the trustworthiness of qualitative research. If a study demonstrates credibility and fittingness, the study is also said to possess conformability. Polit and Hungler (2004) described it as a standard for evaluating data quality and refer to the neutrality or objectivity of the data as an agreement between two or more dependent persons that data is similar. Conformability, therefore, is a strategy that ascertains neutrality by ensuring that the findings are free from bias. The Researcher confirms that the research findings are significantly free from bias and that all possible biases have been acknowledged and addressed in previous sessions of this chapter.

3.14 Credibility

Credibility is demonstrated when participants recognize the reported research findings as their own experiences (Streubert et al., 2003). It is the truth of how the participants know and experience the phenomenon under study.

To ensure credibility in this study, the researcher established good interpersonal relationship and spent sufficient time with the participants to assure a certain level of familiarity with participants. This ensured that participants were able to narrate their experiences without withholding information that they would otherwise have found difficult to share with a total stranger. Conclusions drawn from this study were also cross-checked by the two supervisors.

3.15 Ethical Considerations

In the context of any study, it is important to avoid physical and psychological injury to the participants. Protecting the rights of individuals in any given study is of utmost importance to the researcher. To ensure this safety, various precautionary measures were taken into consideration in the course of this study.

A letter was obtained from the School of Nursing for permission to conduct the research at Ridge Hospital was provided (Appendix D). Permission was also sought from the

Deputy Director of Nursing Services of the Obstetrics and Gynaecology unit; Doctor in-charge & Deputy Director Nursing Services of HIV/AIDS unit through the Medical Superintendent and the Deputy Director Nursing Services in-charge of the Ridge Hospital (Appendix D). This letter enabled the researcher to gain access to the facility and the participants in order to conduct the research.

Matters concerning informed consent, confidentiality, anonymity, risk and benefits, freedom to participate or withdraw were all considered and discussed with participants. The purpose of the study was also explained to the participants in order to gain their consent for the study. Consent forms (Appendix B) were provided for participants to sign and the instructions on the consent forms were provided and explained to participants in either Twi, Ewe or English based on the preference of the participant. After the participants had accepted to partake in the research, the consent forms were given to them to either sign or thumbprint depending on their educational backgrounds. An information sheet was also included and explained to the participants.

For privacy and confidentiality to be ensured, the researcher chose to interview participants individually on one-on-one basis at any place convenient to the participant. The participants were assured that any information given by them will remain confidential and will be used only for the purposes of the research.The researcher explained the nature and purpose of the research to the participants several times and questions raised were duly addressed. Only participants that gave their consent were interviewed.

The participants were informed about the right to withdraw from the study and assured that withdrawing would not affect them in any way. The potential benefits of the study were also explained to each participant. Participants were told that the study would help improve or make life better for pregnant women diagnosed with HIV/AIDS in the future. The researcher anticipated some psychological trauma on the part of participants with regards to stigma and discrimination associated with HIV/AIDS and arranged for an HIV counsellor or clinical psychologist to be available to counsel participants should any of them break down.

To maintain anonymity, the identities of the interviewees and the information gathered from them were coded alphabetically. For example participants were labelled A, B and C; and the data collected was kept separately from other documents under lock and key in the School of Nursing.

CHAPTER 4

FINDINGS

4.0 Introduction

The study explored the experiences of pregnant mothers diagnosed with HIV/AIDS. This chapter presents the findings of interviews conducted with ten (10) pregnant mothers diagnosed with HIV/AIDS.

It is divided into 2 main sections; section one provides the demographic characteristics of respondents while section two presents the main results based on the study objectives.

4.1 Demographic Characteristics of Respondents

The study involved ten (10) respondents. Each of them was interviewed separately. All the respondents were pregnant women diagnosed with HIV/AIDS. Out of the ten (10) respondents interviewed, two (2) were Muslims and eight (8) were Christians. Their ages ranged from 24 to 42 years with an average age of 32 years. The marital status of respondents showed that all of them were married before testing positive. However, two (2) got divorced because of their HIV positive status. The ten (10) respondents found out about their HIV positive status during antenatal clinic. Regarding the number of children of respondents, it was revealed that, only two did not have children at the time of the interview. The other 8 respondents had at least a child.

The gestation periods of the pregnant women ranged from four to 8 months, while two respondents had delivered two weeks before the interview was conducted.

In terms of educational levels, only 1 respondent out of the 10 had had no formal education, four had JHS education, three had SHS education and one had primary education while one had tertiary education. Regarding occupation, one respondent was a teacher while the four were housewives. Also, three were petty traders while 1 worked as a hairdresser. Another respondent reported that she worked as a hotel attendant.

4.2 Narrative Summary of Participants' Demographic Data[1]

1. **Participant A_1(Amina)**

   Amina is a 33 year old mother who lives with her husband at John Teye, She does not have any formal education and is a Muslim by religion. She is a petty seller who hawks shoes.She has had two deliveries; one child is alive and the other dead; and was five (5) months pregnant at the time of the interview. She suspects that her 2 year old son must have died of HIV/AIDS.

2. **Participant B_1(Nana)**

   Nana is 24 years old and was six months pregnant at that time. She is a Senior High School graduate and a hair dresser by profession. She was married and living with her husband and was diagnosed with HIV/ AIDS whilespregnant with her first baby.

3. **PartcipantC$_1$(Ajo)**

   Ajo is a 36 year old happily married SHS graduate.Sheis a house keeper and married with 2 children and all were alive. Shewas 8months pregnant. She is a Christian and a chorister. The husband has tested negative as well as their two children.

4. **Participant D_1(Serwaa)**

   Serwaa is a 34 year old lady with four children, and lives at Fadama. She is a JHS leaver and a petty trader (sells tomatoes at home) who hasa two-week old baby. She is a Christian, married and lives with her husband. She was diagnosed with HIV/AIDs in her eighth month of gestation, went into premature labourupon hearing her HIV

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[1] A Socio Demographic Table of Participants' data can be found in Appendix E

positive status. Her husband and 2 children have tested negative. She however hasa son with another man, who has tested positive.

5. **Participant E_1(Afia)**

   Afia was a 36 year-old lady who lives in Aplaku with her husband. She has four children with the fourth one being only two weeks old at the time of the interview. Her educational level was primary four. She is a house wife and a Christian. All the 3 children had tested negative. Her husband has refused to undergo the HIV test.

6. **Participant F_1(Afua)**

   Afua is a 27 year-old lady who lives in Ashongman. She is a hair dresser and was 6 months pregnant. She got married about 8months ago, but when she became pregnant, her husband sent her to a clinic in the Accra metropolis (she could not remember the name) for HIV Testing. When she tested positive, her husband divorced her and started telling everyone who cared to listen that she has HIV/AIDS. She had completed JHS.

7. **Participant G_1(Adwoa)**

   Adwoa is 32 years old; and married with 1 child. She was 6months pregnant, and lives in Teshie. She is a house wife. She did not want to hear anything about HIV because the mother died of HIV/AIDS five years ago and has since been stigmatized by people. Her husband has tested HIV negative as well as her 2 year old child.

8. **Participant H_1(Yaa)**

   Yaa is a 42year-old teacher in one of the private Junior High Schools in Accra; she was 4months pregnant but divorced due toHIV infection. She lives in La. She got married 8 years ago and has now achieved her 1st pregnancy. She is a Christian and has university education. She was diagnosed with HIV at routine ante natal test and counselling.

9. **Participant I_1 (Ama)**

   Ama is 28 years old and a hotel attendant. Her educational level is SHS. She got married at an early age of 22. She had 4 miscarriages before her current pregnancy. She is 7 months pregnant, and was diagnosed with HIV/AIDS through routine antenatalcounselling and testing for HIV/AIDS. Her husband divorced her immediately after her disclosure ofher HIV status to him.

10. **Participant J_1 (Rukia)**

    Rukia is a 32 year-old hair dresser, married and lives with her husband at Abeka-Lapaz. She is a Muslim and has two children. She was 5 months pregnant. She was diagnosed with HIV/AIDS at routine ante natal counselling and testing, but has refused to disclose her positive status to her husband, who is apparently on ART as well. According to her, since the husband has been on ART for some time without informing her of his condition, she sees no need to disclose her status to him. She hides her drugs in her ladies' bag where her husband cannot find them. Her educational level is JHS. All the two children have tested negative.

4.3 Discovery and Diagnosis of HIV/AIDS in Pregnant Women

Counselling and testing for HIV has become routine at antenatal clinic. The routine testing is aimed at prevention of mother-to-child transmission of HIV. The respondents discovered their HIV status during the routine screening process and the diagnosis was later confirmed. Some of the respondents initially declined to be tested for HIV until the latter part of their pregnancy. The respondents indicated that they got to know of their HIV-positive status at the antenatal clinic. Amina who expressed the conviction that her son died of HIV/AIDS after several visits to hospitals proved futile said, "when I started attending the antenatal clinic at Ridge hospital, it was there that it was detected I had the HIV infection"

The discovery of HIV was accompanied by negative emotions such as fear and suicidal thoughts. Fear is central to HIV counselling and testing because of the perceived deadly nature of HIV/AIDS. This was confirmed by Ama, a 28 year old married woman who in her account said that she feared she would test positive though her baby could be saved from the infection as a result of early diagnosis. She went on to say that she reluctantly took the test and true to her fears, she tested positive.

Some of the respondents underwent HIV testing during their first visit to ANC, while others waited and did the test at the later stage of pregnancy. Some did not believe the results so they went to other clinics for confirmation. Nana narrated her experience as follows:

> I attended antenatal clinic at Ridge hospital. It was my first visit at the antenatal clinic that I was diagnosed as having HIV/AIDS. It was a shock to me. I did not believe it. I went to another facility, LEKMA hospital at Teshie within the metropolis to be sure of the diagnosis and there it was confirmed that I had the virus.

Routine testing and counselling was done at most antenatal clinics although treatment was only available in some clinics/hospitals within the metropolis. For example Ajo, a 36 year old housekeeper who was put on HIV/AIDS treatment at the Ridge hospital after she tested positive revealed:

> I was diagnosed with HIV/AIDS when I got pregnant and was attending antenatal clinic at Palladium clinic, James Town. When I was diagnosed, I was referred by the midwives to go to Ridge hospital in Accra for treatment.

Due to fear, some women sometimes hesitate or refuse the test at first counselling. Serwaa who lived in Fadama and used to work as a security officer with a Bank portrayed such attitude when she recounted her experience:

> I was diagnosed as HIV/AIDS when I was pregnant and went to antenatal clinic. In fact, I was seven months before I went to the clinic. I was counselled and offered the test but I declined the first time. I accepted the test on the second visit when I was 8 months pregnant

The hesitation Serwaa demonstrated delayed the diagnosis of the HIV positive status and such situations could influence the extent to which the child is protected against acquiring the infection.

The antenatal clinic therefore is an avenue where most pregnant women become aware of their HIV status. Some respondents recounted how their woes started and the euphoria that accompanied the pregnancy suddenly was cut short by the HIV positive status. Anxiety, tension and fear factors were the predominant attributes they experienced whenever they agreed to be counselled and tested for HIV.

4.4 Reaction to HIV/AIDS Diagnosis

The respondents generally demonstrated negative reactions ranging from emotional crisis to suicidal thoughts. They were gripped with fear and shock following the disclosure of their HIV-positive results. One respondent indicated that she was happy that at least testing will help prevent her child from the infection. Amina, a shoe seller with one child and a 5 month pregnancy typified such situation in the following statement:

> I was filled with bitterness and intense anger directed towards my husband because of his womanizing behaviours. I was really bitter and I wept. I knew for a fact that my husband infected me.

The immediate reaction of this respondent was to weep and accuse the husband for her predicament. Amina also contemplated suicide:

> Immediately my mind told me to commit suicide but decided against that upon second thought. Then I later decided to divorce my husband. But here is the case, I am already pregnant. Where will I go with this pregnancy?

The disclosure of HIV-positive results to a patient sometimes also led to negative reactions such as shock, loss of hope and thoughts of the end of life for the person. Ajo who got to know of her status after attending antenatal clinic at Palladium Clinic at James Town narrated her experience:

> I wept bitterly, all my eyes got swollen up, I could not see clearly, my eyes were filled with so much tears that I was nearly knocked down by a moving vehicle and I wept because of the stigma attached to HIV/AIDS. I decided to go and lie in the middle of the road so I can be run over by a moving vehicle to end my life.

Afia, a 36 year old married woman with 4 children was equally in a state of shock and confusion as portrayed in her story:

> I wept bitterly due to the nature of the disease. I lost appetite completely for several days and was very confused and could not understand how I contracted this illness. I said life was not worth living, but I thought of the children and decided not to do anything hasty but rather to take the drugs and live to see my children grow.

Ama, who reluctantly tested for HIV due to the fear she has about the disease, reported that her whole world changed because she tested positive. She lamented:

> I cried bitterly, I was shocked and I denied it because I heard the disease kills. And if you have AIDS then you are a prostitute. The diagnosis is untimely. The time is wrong. No, pregnancy should not be part of this

> disaster. I wanted to drink some poison and die because I cannot be the source of infection of my innocent baby. It was a difficult situation.

To some respondents,HIV degrades and devalues one as a human beingand people disrespect you for being HIV-positive. This was portrayed in Rukia's reaction when she tested positive. She explained that she was sad and depressed and decided to take her life though it is forbidden by her religion because she thought she could not live with HIV all her life.

It is important to note that the fear associated with HIV has a general pattern. This fear and anxiety is caused by the stigma and discrimination people experience when they test positive for HIV. It was observed in the study that respondents reacted negatively when their diagnosis showed that they were positive which was expressed as shock, worry, anxiety, sadness and thoughts of committing suicide.

4.5 Perception of HIV/AIDS Counselling and Testing

The fact that the counselling was about HIV/AIDS was a major source of worry for the respondents. The perception that HIV/AIDS was a deadly or bad disease was the main reason for the negative perceptions about the counselling and testing. Thus although they were sometimes appreciative and they did the counselling and testing as was the case of Amina, because she found her status for the sake of her baby, it was not without anxiety and worry. She remarked:

> That experience is full of anxiety and worries since you cannot tell what the outcome will be. Although I am relieved that I did the HIV test after counselling, the impact of knowing I have HIV is still a great burden on my heart.

Nana, a 24 year old married woman, was also much concerned about HIV counselling and testing because of anxiety about its outcome. According to her, "the counselling and testing time is with mixed feelings because you don't know what the outcome is going to be. I was quite confident that I could come out clean until I had the shock of my life when the result was positive."

Similarly, Ajo a 36 year old SHS graduate and a housekeeper indicated that her heart was beating withfear, and though she managed to control herself, she was worried about having to live with HIV/AIDS. Afia, another respondent, indicated that counselling and testing was good but she went through a lot of physiological problems when she was counselled and tested. For her,

> Even though the counselling and testing is good, my heart was beating very fast with great worry and anxiety. I was also very scared of the outcome of the results because of the stigma attached to the disease.

Another respondent, Adjoa, a 32 year old woman married with a child even cursed the day she tested positive and stated that she would not like to remember that day in her life because of the perceived stigma associated with the condition. She stated that "I was never happy to do any test left alone HIV test. I was never happy to do the test because of HIV associatedproblems such as stigma."

Invariably the negative perceptions about HIV counselling and testing also tend to make some women associate HIV with death. Ama, a 28 year old woman who works as a hotel attendant remarked that testing positive has changedher whole world.

4.6 Disclosure of HIV Positive Status

The news about HIV/AIDS was generally received with sadness and panic. The disease is perceived to be dreadful and fearful. The disclosure of a positive status is therefore a major problem for most respondents due to the stigma and discrimination such disclosures come with. As a result some respondents did not disclose their status to anyone for fear of being discriminated against. The negative consequences associated with disclosure such as loss of marriage, rejection, isolation, stigmatization and discrimination were all reported by respondents. Despite these, some respondents disclosed their status to their spouses and other closed relatives such as mothers, sisters, brothers and significant others.

4.7 Outcome of Status Disclosure

The Respondents in the study recounted what happened to them following the disclosure of their HIV positive status to their spouse or family members. While some enjoyed love, care and support others were abandoned and discriminated against by their own loved ones. One of those who received a positive reaction was Ajo, who was anxious and decided to inform the husband about her diagnosis. She said:

> I was weeping after informing him about what happened at the clinic. He then warned me that if I do not stop weeping and we get home and people asked why I was crying he could not get anything to tell them, so he further warned that if I do not stop the weeping he will leave me or run away from me.

Another respondent Afua, who was divorced by the husband following disclosure of her status, found support from her former boyfriend whom she also shared the news with. She indicated that:

> I told my former boyfriend who treats me very well. He encouraged me to report to the clinic and that because his friend also had the same HIV/AIDS but because she was put on the ARV drugs, his children tested negative.

On the other hand, Afia, was rejected by her husband and mother after disclosing her status to them.

> I told my mother, who brought me up. She sat a while in silence and said it does not matter. I also told my husband whose attitude towards me changed immediately. He started picking quarrels with me, though he was not a quick tempered person. He sometimes packed my belongings out, that I should leave the house. He gets angry at the least provocation. He told me I will live with hunger and sleep with hunger in his house.

She continued:

> He bought us a bag of rice without anything to eat it with. I am even tired of eating the rice. My mother who has been very close to me has rejected me and she has never visited me again (she sobs). I know it's because of disclosing my HIV status to her.

The stories of the women indicated that discovery of HIV positive status was devastating to most of them. Considering the stigma and discrimination associated with HIV, most of the respondents were very protective of information about their status. Somepreferred to tell their husbands while others informed their family members. The outcome of disclosing their HIV status to close relations sometimes ended in rejection. When that happens, the other option was for the respondents to look up to support from health care professionals. However, the attitude of some midwives was not helpful to these pregnant women who had to battle with physiological effects of pregnancy and their HIV positive status.

4.8 Attitude of Health Professionals

Respondents recounted negative treatment they received from health professionals. These included maltreatment, shouting, neglect and contempt by the midwives. Others also mentioned that they were discriminated against and stigmatized. This was in spite of the fact that midwives are trained to demonstrate care and love to pregnant women and those in labour.

Afia, one of the respondents had this to say about the attitude of health professionals towards her:

> When I went to the labour ward, the nurses did not want to attend to me and when I delivered the baby, the baby was placed on my abdomen while I was bleeding profusely. I called the nurses for help but no nurse came to attend to me. Even another nurse was not happy about my treatment and asked why the baby was still on my abdomen whilst I was bleeding and the baby was also not bathed. The junior nurse came to give me injection to stop the bleeding, took my baby away for bathing, before she removed the placenta. The nurses treated me badly.

Midwives spend a lot of time with pregnant women from conception to delivery. They are expected to support their clients without any discrimination. However, respondents reported negative attitudes of midwives such as shouting at clients, discrimination, neglect, intolerance and abuse of clients’ anonymity. Respondents also indicated how these attitudes affected them.

4.9 Effect of Negative Attitudes of Midwives on HIV/AIDS Positive Women

a) Prejudice

The manner in which midwives related to the respondents created emotional pain for some of them. Some respondents felt the health care professionals were prejudiced against them because of their status. Serwaa, a petty trader narrated her experience as follows:

> During the delivery of my baby at the labour ward all the midwives neglected me. I called them several times but they did not mind that I was an HIV pregnant woman. I pushed and the baby fell and hit his head on the floor. When a doctor made the effort to pick the baby from the floor of the labour ward, all the midwives shouted "be careful she has HIV/ AIDS". One of the mid-wives asked me, are you now coming to the hospital,when you are almost at the point of death? I was diagnosed in my eighth month of pregnancy.

Rukia was surprised to know that the midwife who she knew was HIV positive also maltreated her. She expected some support from the midwives but felt that even the one who should understand her plight was worse off. The negative attitude of the midwives made some of them to deliberately delay attending to pregnant women who were HIV positive.

b) Breach of Trust and Confidentiality

Afua, whose marriage broke down because of HIV was so worried about the way nurses at the OPD treated them.

> Some of the nurses, especially at the OPD when they see that HIV code "279" is written in our folders, the young nurses start, whispering among themselves and behave in funny ways towards us. But I do not mind because I have HIV today. They are young and are now coming; they

> don't know what they will meet. The senior nurses talk well to us but the younger nurses, don't respect and behave towards people anyhow.

The trust and confidence respondents had in midwives was breached. It was found that a code (279) was used to label their folders which made it clear for other people to know that they were HIV-positive patients.

c) Stigma and Discrimination

Respondents also reported neglect and indiscreet way in which midwives disclosed their status if another person wants to assist them. The attitude of the midwives was the same when HIV positive pregnant women attempt to assist others. Adjoa recounted her experience:

> I tried to help a patient who could not lift her bucket, suddenly the nurse shouted at the patient, eh! Do you know the disease she is suffering from? Everybody got to know I have HIV/AIDS and the way they looked at me, I was embarrassed. I still feel the pain as I speak to you now.

Stigmatization and discrimination especially by midwives was worrying given their training in the care of pregnant women. Midwives generally did not want to associate themselves with HIV-positive pregnant women especially during labour.

d) Inhuman Treatment

Some respondents were concerned about the inhuman treatment they receive from midwives. They mentioned that midwives treated them with disrespect because of their HIV status. Ama, a 28 year old divorcee and hotel attendant narrated her experience. According to her, "health care professionals treat us as people who are not even supposed to report at the clinic. They scream at us with unkind and unpleasant words." She emotionally asks: "Tell me if I had a choice, will I go for HIV, worst of all when I am pregnant?" It was found that screaming and the use of unkind words by midwives was a major concern for most of the respondents.

In summary, the kind of treatment given to HIV-positive pregnant women by midwives was highly undesirable. Midwives who are supposed to care and empathise with HIV pregnant women were alleged to be shouting at them, ignoring them, and insulting them as if they were children.

4.10 Experiences of HIV Positive Pregnant Women on ARV

Most of the respondents gave positive accounts what their use of ARV drugs had brought to them. They mentioned that they were highly conscious of the fact that the drug helps to prevent children from HIV infection, make them strong and healthy and prolongs their lives. However, some were not happy with the stress and difficulties they undergo to collect and take the drugs. They cited the following as some of the challenges they faced:

The need for frequent trips to the ART centre to collect their drugs was identified by respondents as one their main challenges. They complained about the small quantity of drugs given per visit, and the resulting need to visit the centre at short intervals.

Respondents also complained about the unnecessarily long hours they had to spend waiting to be attended to each time they visited the clinic to pick their ARV drugs.

According to Amina:

> One has to spend hours upon hours to collect them. Sometimes I wish I could collect for a period of three or four months so I will not be coming to the clinic often that will make me rest.

Some respondents also mentioned that long hours spent at the clinic prevented them from working on those days, a situation which further decreases their incomes. The burden of transportation is further compounded by the fact that some respondents travel far from their communities to maintain anonymity. Adwoa explained this situation in the following words:

> In order for people not to identify us in our community, I go far away to ARV clinic to collect my drugs. This makes me spend more money for the drugs on transport. I am not working and this makes life very difficult for me.

Serwaa, another respondent also affirmed that they sometimes spend the whole day at the hospital waiting to collect these drugs; and that the delay in giving attention at the ARV clinic was a worry to her.

The cost element associated with the collection of ARV drugs was also identified as a major problem for the respondents, with most of the respondents lamenting the financial burden HIV/AIDS has placed on them. They complained that, cost of transport, regular laboratory tests and other expenses increased their financial needs.

Amina captured this concern as follows,

> Financial support is one of our challenges. We do laboratory investigations every now and then, they call them CD4. Coming to the laboratory often places a financial burden on us and this makes life difficult for us.

Respondents also revealed a persistent preoccupation withthe possibility of people finding out about their positive status. They reported having to hide to take their ARV drugs, since they considered being seen taking the drugsas tantamount to disclosure of one’s status. They also choose to travel far from their communities to collect their drugs in order to avoid running into people who may know them. Adwoa disclosed the extent to which they go to hide their status:

> I cannot go and collect the drugs at LEKMA else I will meet somebody I know at LEKMA who will get to know that I am HIV positive. And from there, the person can go and expose me and be pointing fingers at me that I have AIDS and everybody within the community will get to know about my HIV status. That is why we go far away from our communities to collect our drugs.

4.11 Social Support for HIV Pregnant Women

Given the nature of the HIV disease and the stigma associated with it, it is important that patients are given support in the form of financial, emotional support and empathy by family members, midwives, and partners/spouses. The individuals also have to help themselves in such situations. The respondents reported varied forms of support from family members, midwives, partners and self-support.

a) Family Support

Most respondents were displeased with the rejection and neglect some family members extended to them when they got to know of their HIV-positive status. Some however, mentioned that they received tremendous support and care from family members such as mothers, sisters and other relatives. Nana a 24 year old married woman who was six (6) months pregnant was disappointed at her elder sister's behaviour after confiding in her about her HIV-positive status. Nana said she lost the companionship she used to get from her elder sister and other siblings because of herHIV positive status;she explained the events that led to that:

> I confided in my elder sister but she went to tell other relations. She used to visit me often and her children come on vacation in my house but ever

> since I told her about my diagnosis she had not visited me again. My junior sister who is a student visited me, I gave her water she didn't also take, I gave food she didn't eat and offered her money which she didn't also take. So I asked myself is the HIV/AIDS virus on the money also? I felt so sad.

Some respondents experienced positive reactions from family members such as mother, sisters, brothers, uncles. Serwaa typified this reaction as follows when she was diagnosed with HIV/AIDS:

> I told my husband, my mother, my sister, my brothers, my uncles and all other relations but they do not discriminate against me. They visit me, I visit them, I cook food and we all put our hands in one bowl and eat together and we are all very free.

Another respondent who was happy with the support and care her brother showed her when she was diagnosed with HIV/AIDS was Adjoa, she remarked:

> I informed my brother, my auntie and my brother. My brother pledged me his support and said he knew I picked the infection from my mother.

But the reaction was negative for some as indicated by Afia whose mother rejected her because of her HIV-positive status. Afia commented that:

> It was my mother and husband I told about the diagnosis and ever since my mother has also rejected me (she cried).

Another respondent Yaa also captured the negative reaction she received as follows:

> It's only my sister who supports me emotionally, and apart from that since nobody knows, I don't have any support.

Family support was found to be important for respondents as the care, love and empathy shown by family members was very important for their health. However, this kind of support was not extended to some respondents as they seriously were denied when family members got to know of their status.

b) Partner Support

Support is crucial in the life of HIV-positive patients. In particular, spousal support accounts for a significant improvement in the health of such patients. Some respondents in this regard, mentioned that their spouses were very supportive.

For example Ajo, a 36 year old housekeeper married with two children was very appreciative of the care and support extended to her by her partner indicated that:

> I must say my husband supported and treated me so well that I always forget I am HIV positive. The day my husband has time, he even goes to clinic with me to collect the drugs. He really supports me and I am grateful to God for a man like him. He consoles me a lot when I am depressed, he tells me he does not want to see me in a sad mood.

Ajo continued:

> Sometimes he wakes up early to go and queue for the drugs before I follow up later in the day due to the congestion at the clinic he has even become one of the ambassadors fighting for HIV at the National HIV Control Programme. He is doing all this in support of me although he himself has tested negative.

Serwaa who used to work as a security guard with Ghana Commercial Bank also recounted the tremendous support her husband has shown her since getting to know of her HIV status. She remarked:

> My husband takes very good care of me, he loves me more and doesn't want to see me sad, treats me well so that I don't die and leave him. He was able to quit his job to help me care for the children.

However, most respondents also indicated that, the usual spousal support that they received from their husbands such as money, communication, love and companionship all vanished because of their HIV-positive status.

Afia, a Christian, married with 4 children narrated how she lost the support of her husband due to HIV/AIDS. She said:

> He does not give me money for the house, gets angry easily and picks quarrel with me, with the threat of throwing me out. She said while crying, one time, he said, you will sleep with hunger and leave the house

Another respondent experienced complete lack of support from her husband. She mentioned that, the husband divorced her when she needed him most. Afua, a 27 year old hairdresser claimed:

> My husband divorced me immediately I tested positive and sent me out of the house.He tells everybody around me that I am HIV positive and went to tell all my relations that I am HIV positive but when my relatives asked whether it was true, I denied it.

Similarly, Ama a hotel attendant and SHS graduate recounted how her marriagebroke down when she informed the husband of her HIV-positive status. She commented:

> I told my husband who sacked me out of the house when I told him about the infection. He gave me one week to quit the house for him and I complied since I had no choice. He did not beat me though. I felt worthless and disappointed. Should this happen to me! I heard it happens to people. I never knew it's so close to me. For one week, my husband

> never gave me money, he never talk to me let alone ask of my pregnancy.

In summary spousal support is one very important support respondents dearly needed as married women. Some were given the necessary support by their husbands but most were rejected and divorced instead of being cared for

c) Support from Midwives

A few respondents reported that, some midwives counselled them, encouraged them and empathized with them despite their HIV/AIDS status. Amina, a 33 year old shoe seller with a child, had some good memories of her experience with health workers and stated that some of the midwives were really very nice people. Nana, a 24 year old married woman who is six months pregnant also commended health workers. She remarked that “health care professionals treated me well. Midwives and doctors at the antenatal and ARV clinics talked, counselled and encourage us to live positively”.

d) Social Support from groups and NGOs

Most of the respondents expressed the view that they do not have any form of social support, be it from support groups or NGOs. Some were of the view that this was probably because they did not belong to any group themselves. Amina who indicated that she was not a beneficiary of any social support group expressed that view as follows:

> I don’t receive any support from any NGO. I do not know if it is because I have not discussed my HIV status to anyone.

The few who were members of support groups however spoke favourably of the support they are receiving through such networks. Ajo for example was happy and indicated that her network support was a source of hope and joy:

> I belong to a support group called Model of Hope. The model of hope members who are also HIV positive members encourage me when we meet that makes me very happy.

Ama who was desperately in need of help from such support groups remarked:

> I do not know of any NGO which can help me either financially or in kind. If you know any, I am too willing to receive help from them.

Also Rukia, who was unaware of the fact that social support groups or NGOs provide help to HIV patients, stated that, “no NGO helps me, and I do not know of any NGO which helps people”.

In effect most respondents generally did not benefit from support groups because they were unaware such groups exist that provide support to HIV/AIDS individuals. The few who belonged however acknowledged the benefits from such support groups

e) Self Support

Some respondents recounted how they struggled to support themselves with their meagre incomes. They indicated that they are not able to bear fully the financial cost associated with transportation, check-ups and treatment. Yaa, a divorcee explained that she only lived on the little she receives as monthly salary since her husband no longer supports her. Ama also indicated that “My salary is too small to meet my needs and regular check-ups make me spend so much”.

Respondents lamented that they had to rely on their little salary to cushion the financial burden associated with the treatment and cost of visiting the clinic frequently for the ARV drugs.

4.12 Coping Strategy

Respondents indicated that they relied on prayers to cope with their present predicament. God or Allah was looked up to as the last resort and source of healing for all the respondents interviewed.

Prayer was utilized as a coping strategy by both Christians and Moslems. Since HIV/AIDS has no cure, they turned to God or Allah who they believe is supreme and would come to their rescue. Amina said:

> You know the diagnosis of HIV itself diminishes the happiness and joy in the individual. It renders you unhappy and moody all the time. So I pray to Allah to give me strength daily to do that which is expected of me.

Nana who recounted how she gets empowered by God through prayers remarked:

> I try to encourage myself in the Lord; and I pray for strength from above to keep me going.

Ajo also said she prays to "God for strength from above and that is how I cope daily."

Some respondents were even hoping for a miraculous healing from God through their prayers. Serwaa stated that she believed in God and had been praying together with her husband, who happens to be a pastor, for God to heal her. Similarly, Afia who demonstrated confidence in the healing powers of God commented that she looked up to God to heal her, and remove this disease from her.

Adjoa said that:

> I am a child of God. I believe in him, I pray to God every day that I do not fall sick for my condition to deteriorate.

Yaa who acknowledged her confidence in prayers indicated that:

> I pray and read my bible everyday asking God for forgiveness of my sins and to heal me. I also attend church regularly and also work when my strength permits me.

Rukia indicated she had placed her hope in Great Allah to see her through the difficult moments.

Prayer was identified as a major source of help for respondents. Thus, faith in God or Allah was the major coping mechanism respondents utilized to bear with their current situation.

CHAPTER 5

DISCUSSION

5.0 Introduction

The present study examined the experiences of pregnant mothers diagnosed with HIV/AIDS. Specifically, the study sought to understand the emotional reactions of pregnant mothers diagnosed with HIV/AIDS, explored the clinical or social support systems available for pregnant mothers diagnosed with HIV/AIDS, and finally determine the coping strategies employed by pregnant mothers diagnosed with HIV/AIDS to cope with their predicament. This chapter provides a detailed discussion of the findings in line with the above objectives. The study uncovered several issues which border on the experiences pregnant mothers diagnosed with HIV/AIDS goes through. These experiences ranged from worry and anxiety often associated with diagnosis and subsequently living with the disease. Psychological and emotional problems associated with the disease as well as the coping mechanisms the respondents utilized have been identified.

5.1 Discovery and Diagnosis of HIV in Pregnant Women

The current study showed that, all the respondents got to know of their HIV-positive status during antenatal clinic. This implies that antenatal services provide an important means by which pregnant women get to know of their status as well as prevent the unborn baby from infection. The findings showed that counselling and testing was good but was associated with anxieties, worries and fear. According to Mokhoka (2000) and van Dyk (2008) anxieties, worry and fear which are often associated with HIV/AIDS counselling and testing is a common psychological problem every individual with HIV/AIDS will experience because of the perception that positive diagnosis is a death sentence.

Most of the respondents indicated that counselling and testing for HIV/AIDS was psychologically traumatizing. None of the respondents reported positive feelings about counselling and testing for HIV/AIDS. Though ARV drugs are available in the event that one who becomes positive can use to live a longer life, it seems the general fear associated with the disease gripped them. It was also obvious that, some respondents fear and anxiety was triggered by the fact that they will be stigmatized if they tested positive

5.2 Disclosure of HIV Positive Status

According to Nsabagasani and Yoder (2006), disclosure of HIV positive result is very critical to HIV prevention. However, the findings obtained in this study show that disclosure of HIV positive result caused immediate distress. Thus, most pregnant women diagnosed of HIV find themselves in a fixed *"to tell or not to tell"*. Most of the respondents disclosed their status to their partners or family members.

Most respondents lost their marriages, friends, relatives and were stigmatized by people because of disclosure of their HIV-positive status. This is in line with the view that, disclosure of HIV-positive status is sometimes associated with rejection and discrimination by spouse, loss of marriage and relatives (Medley & Garcia-Moreno, 2004). They mentioned that disclosure of HIV-positive result by pregnant women was associated with accusations of infidelity, abandonment and discrimination.

In addition, disclosure was found to lead to loss of happiness and joy in marriage as well as change in attitude of family members towards pregnant women with HIV/AIDS. This results fall in line with the assertion that disclosure of HIV-positive status could lead to divorce, separation or abandonment of intimate partners (DeMatteoet al., 2002).

Despite the negative consequences associated with disclosure of HIV-positive status by pregnant women, some respondents indicated that disclosure was associated with care and comfort especially from spouses and other relatives. According to Collins and Miller (1994), disclosure of HIV-positive status helps women in terms of reproductive choices as well as psychosocial support (Deribeet al., 2008). Some respondents reported that, their spouses showed them care and love instead of rejection and abandonment when they disclosed their HIV-positive status to them. It has also been reported that disclosure leads to lower levels of stress and better psychological health for women than non-disclosure.

Generally, some respondents reported that they were relieved after disclosing their status. However, some respondents did not disclose their status to anyone due to fear of discrimination, accusations and rejection. This lends support to the view espoused by Deribe et al. (2008) most women do not disclose their sero-positive status especially to their spouse because the partner might get angry with them, fear of separation/divorce or accusation of infidelity. The reason for non-disclosure was also emphasized by Nsabagasani and Yoder (2006) who stated that, disclosure of HIV test result was a very complex, difficult personal matter that requires communication about a potentially life threatening stigmatized and transmissible infection. It was obvious from the study that, some respondents did not disclose their status to their partners because they did not want to break their home or experience rejection, accusation of infidelity and loss of joy and happiness.

5.3 Attitude of Health Professionals

The study revealed that being diagnosed with HIV/AIDS was associated with a lot of negative experiences. Most of the HIV pregnant women reported that negative attitude of midwives during antenatal and delivery was a major source of concern. Though midwives were trained to show love and care, most of them tended to shout at their clients, neglect and even expose their status to people at the clinic. This behaviour of some midwives demonstrate negative attitude towards pregnant women diagnosed with HIV/AIDS.

Regarding the attitude of midwives, a respondent remarked: “Midwives shout at us as if we are children, they can ask you to go home without collecting your drugs”. This outcome is consistent with previous results. In particular, Mbanya et al., (2001) reported that midwives generally demonstrated negative and discriminatory attitude towards pregnant women.

Despite the fact that most midwives were associated with negative attitudes towards HIV infected women, there were still some who demonstrated positive attitudes such as care, encouragement, empathy and love towards their clients. Thus, not all respondents were treated badly such as shouted at, neglected and ignored during antenatal and delivery. This finding lends support to previous results by Oyeyemi & Bello, 2006 and Reis et al.; 2005. These researchers pointed out that though most studies reported negative and discriminatory attitude of midwives towards HIV pregnant women, some midwives tended to demonstrate more empathetic attitude, care, love, and encouraged their clients to live healthy lives.

5.4 Experiences of HIV Positive Women on ARV

Respondents reported hiding the drugs to avoid stigma. There were some who could not access medication sometimes because of inadequate stock/supply and transport cost. Others also reported side effects of the medication as a major challenge however the motivation to save their babies from being infected encouraged them to take the drugs no matter the discomfort associated with it.

5.5 Social Support for HIV/AIDS diagnosed Pregnant Women

The study found that respondents generally received support from several sources. Specifically, family support, spousal/partner, midwife and self supports were identified and discussed in the study. Social support is an important source of coping for HIV positive patients. This translates to the fact that social support is necessary for the well-being of HIV-positive pregnant women.

It was revealed that the social support net of respondents was very large. It included support from midwives, partners, family and self. This kind of support was very important because as indicated by Compton (2005) a sufficient and large social support net was a major source of increased self-esteem, more effective coping and better physical and psychological health.

The study also observed that, respondents lacked the support required of midwives, partners and family members. It has been reported that, midwives tended to verbally and physically abuse HIV-positive pregnant women as well as neglect them (Dlamini et al., 2007). In addition, Thorpe, Grierson and Pitts (2008) mentioned that rather than support and care for them during labour and antenatal sessions, midwives rather discriminated against women.

According to Compton (2005) studies have shown that when individuals seek out social support they are likely to experience increased optimism and more perceived control. It is therefore important for pregnant women diagnosed of HIV/AIDS to disclose their status and seek opportunities to receive social support.

An American study conducted by Goggin et al. (2001) asked HIV positive women what advice they would like to give other women and the most frequent suggestions given were to maintain a positive attitude, create a support system for oneself and take care of oneself. According to them, “with regard to awareness of a limited life span, alienation, and stigma, the women’s responses may indicate how important HIV resources can be in providing social support, reducing alienation, and fostering empowerment. It was further revealed that some spouses/partners did not accept their wives when they got to know of their HIV-positive status. This situation has been found to be responsible for why most women hesitate to disclose their status to their partner for fear of being physically assaulted, rejected or abandoned.

Finally, another component of support identified to provide a significantly impact on the psychological problems associated with HIV-positive status was HIV support groups. According to Dadich (2006), support groups serve as an important tool for the improvement and enhancement of the physical and psychological well-being of HIV-positive women. The current study observed that a respondents' psychological and physical well-being was significantly being impacted positively by the social group she has joined (i.e. Model of Hope Group). However, it was also observed that most of the respondents neither lacked knowledge of the availability of social support groups but were not associated with any.

5.6 Coping Strategies

It was observed that respondents utilized prayers as a coping strategy to bear with their predicament. Most respondents seemed to look up to God or Allah for healing and intervention. This lends support to the assertion by Lewis and Brown (2002) that female adolescents infected with HIV used strategies such as praying, listening to music, thinking about good things and being close to someone you care about as a buffer against the tension, fear and depression that come with HIV-positive diagnosis.

Similarly, most of the respondents reaffirmed their faith in the Supreme Being and generally expected healing from him. As mentioned by scholars, spirituality is a form of social support and psychological adaptation for HIV positive persons because it serves as an important source of relief from discomfort and distress (Simoni, Frick & Huang, 2006; Tuck, McCain & Elswick, 2001). Spirituality has been found to be utilized by women when under stress or depression. This is in agreement with the report by researchers that women are more likely to seek religious consolation, tend to draw more closely to God under circumstances of distress (Ferraro & Kelley-Moore, 2000; Stark, 2002).

Pregnancy is a state in a woman's life that comes with a lot of physiological changes some of which create discomfort for the woman. The experience of reporting for routine check to determine progress of pregnancy only to realise one is HIV positive was reported as emotionally unbearable for these women. The pre and post test experiences of these women were characterised with anxiety, fear, shock and suicidal tendencies. Decision to disclose status led to acceptance or rejection. The rejection also came with stigma and discrimination from spouse, family members and health care professionals particularly midwives. Nevertheless, pregnant women diagnosed with HIV still enjoyed some support from their spouse, family members, social support groups and some supported themselves. The major coping mechanism was prayer and the women were also on ARV which enhanced their quality of life and reduced the risk of transmission of infection to the new born.

CHAPTER 6

SUMMARY AND CONCLUSIONS

6.0 Introduction

This chapter provides a summary of the study, lessons and observations made; the implications for policy makers, medical professionals, families and social groups as well as pregnant women diagnosed of HIV/AIDS.

6.1 Summary

HIV/AIDS patients face several challenges which tend to further impact their health and social well-being. The situation is even more serious with women diagnosed of HIV/AIDS.This study soughtto describe the experiences of women diagnosed withHIV/AIDSusing qualitative descriptive approach. Pregnant women attending antenatal clinic at Ridge Hospital, Accrawere purposively selected and interviewed. After 10 interviews data saturation was attained.

The interviews were tape recorded, transcribed and analysed concurrently. A content analysis was done by coding, categorising and deriving meaning from data text bearing in mind verbatim accounts and context of field experiences. Data was collected over a period of six weekswith consistent follow-up, engagement of the respondents and analysis of the data gathered. Six (6) major themes and twenty three (23) subcategories emerged from the data.

The study revealed that the respondents became aware of their HIV-status during pregnancy when they underwent prevention of mother to child transmission screening. It came as a surprise to them and resulted in negative reactions such as suicidal thoughts, sadness, moodiness, worry. This means psychosocial support is very critical for women tested HIV positive. It was evident from the study that most of the respondents lacked support especially from their spouses and family. Specifically, their spouses and family rejected them upon being aware of the HIV-status. Self-support was also a major problem as most of them depended on their meagre income for survival.It was instructive to note that majority of the respondents, had unfavourable experiences with midwives and other health professionals who attended to them at antenatal clinics.

The patients were categorical that health professionals stigmatized them any time they saw Code 279 (the code for HIV-positive patients at the Ridge Hospital) on their files. Midwives in particular discriminated against them; they treated them with disrespect and prejudice and shouted at them. They were uncomfortable with their foldersbeing labelled with “Code 279”, which made any one handling their files know of their HIV/AIDS status at the antenatal clinic. It came out of the study that the major coping strategy of the women was prayer; they all looked up to God for healing and strength. In addition to prayer they confirmed they depended very much on the ARVs for which reason they could not abandon attendance at the ARV clinics notwithstanding the stigma and long waiting periods at clinic. The mother-to-child strategy of minimising the impact of HIV/AIDS is laudable however, health professionals need to protect the personal integrity of their clients and avoid all acts of discrimination against HIV positive pregnant women. Structures must be put in place to support women who suffer broken relationships as a result of their status. Further studies would have to be done to explore factors influencing the attitude of midwives towards HIV positive women.

6.2 Implications of the Study

This study has relevant implications for policy makers, health administrators,educators and practitioners and social institutions as well women diagnosed with HIV/AIDS.

The results show that notwithstanding the several interventions by those tasked with the management and control of HIV/AIDS, the patients and in particular, pregnant women diagnosed with HIV/AIDScontinue to face significant psychological problems such as depression, anxiety, stress and financial deprivation and support from their spouses and families.

It was evident that the current policy of confidentiality and unauthorized access to patient information was not adequate and needs to be reviewed. It became clear from the study that stigmatization and discrimination of HIV/AIDSpatients remains a challenge of even among health care institutions. It is therefore imperative to place more focus on the continuing education and orientation of health practitioners. Practical programmes and actions for monitoring the attitudes and behaviours of health practitioners need to be updated and implemented in line with the findings of this study.

It may be necessary to include some tips on investment and financial management to enable patients cope better in the absence of financial support. It may be necessary to involve the spiritual leaders of the various faiths of the patients in the therapy team as well.The education of spouses and families must be seen as an integral part of the therapy for HIV/AIDSpatients at the very point of awareness of their status.

6.3 Areas for Future Research

The study on pregnant women diagnosed with HIV/AIDS has brought to the fore a number of other areas requiring further research. As this study had as its focus the experiences of pregnant women with HIV/AIDS, it will be relevant to undertake further studies which will highlight the experiences of other stakeholders mentioned in this study. As an example the researcher is of the view that further studies into the experiences of health care givers with HIV/AIDS pregnant women could provide an understanding that will be relevant in further shaping the curriculum and continuing education of health care givers. A future research which focuses on each major theme mentioned in this study may be necessary to provide deeper insight and recommendations for all stakeholders in the fight against HIV/AIDS in Ghana. As an example a research into the challenges of HIV/AIDS pregnant mothers who face stigmatisation and rejection could provide relevant insights to all stakeholders for an improved management of HIV/AIDS pregnant mothers.

6.4 Limitations of the Study

A study of a subject as this could not be without limitations even though much effort was made to ensure that the findings were not tainted by the limitations. A limitation of the study was the relatively small sample size of ten (10) women and the need to obtain primary data from them. It is assumed that if the sample size were larger more information could have been generated. A further limitation of the study was its inability to establish how faiths other than Christians and Muslims coped with their challenges.

6.5 Field Experiences and Insight Gained

The research offered a unique opportunity for the researcher to confirm the reality of what has been reported in several studies reviewed as part of the literature for this work. The selection of respondentswas a challenge as the pregnant women became highly emotional after their HIV/AIDS diagnosis. The researcher therefore had to empathise with them and allowed time to elapse to enable them regain their confidence and to be in a position to engage in an interview.

Another field experience was the booking of appointments with the respondents; it was insightful to note that the time of interview was as important as the location where the interview was held. A number of the pregnant women diagnosed of HIV/AIDS were concerned about a third party becoming aware of their status. It was especially for this reason that in some cases the interview had to be re-scheduled several times in order to ensure a respondent was most comfortable with the time and venue.The need to remain sensitive at all times when dealing with pregnant women diagnosed of HIV/AIDS became more evident at each stage of the field work.

Some of the respondents expressed their reluctance due to participant fatigue and the researcher had to assure them of confidentiality and the relevance of the study not only to them but also to the society at large. In all cases, after this assurance, the pregnant women with HIV/AIDS became very willing and enthusiastic to respond to the questions posed by the researcher.

The field work provided a relevant insight into how patients and in particular pregnant women with HIV/AIDS are very dissatisfied with the services being offered at the health care centres. The researcher on a number of occasions had to seize the opportunity to counsel and encourage the respondents to help them cope better with their predicament. The researchers' previous knowledge in guidance and counselling was therefore put to practice on several occasions during this field work.

6.6 Conclusion

Pregnant women diagnosed of HIV/AIDS are a unique class of HIV/AIDS patients whose numbers are increasing and therefore require special mention. They are in fact very important because whatever treatment is giving to them has implications for their unborn child.

It is evident from the study that many of the women only become aware of their status when they visit the antenatal clinic which re-emphasises the need to encourage early attendance of antenatal clinic by pregnant mothers. The need for guidance and counselling at the antenatal clinics has also been brought to the fore though this study. This becomes even more important when considered against the background that many of the women face rejection and stigmatisation from families, spouses, friends and health care givers.

The importance of the ARVs was also re-emphasised by the respondents, which calls for another review of the availability of the drugs as well as how best to ensure it reach the women in the right quantities and time. Every effort needs to be made to avoid the situation where the pregnant women with HIV/AIDS cannot have access to the drugs; it is important to keep in focus the well-being of the mother as well as the unborn child.

Health care givers are not only the first point of contact of the pregnant women with HIV/AIDS, they are in fact in a continuous and growing relationship with the women. It is therefore critical for doctors, nurses and midwives to be trained and educated on the need to accept the women and treat them with respect at all times.

6.7 Recommendations

The following recommendations are as a result of the findings and observations made from the above study:

- There is a need to review and re-structure the policy of confidentiality in health care institutions. The policy should seek to make it unattractive for people in privileged positions in our health institutions to usepatients’ information against them. This may include introducing stiffer punishments on any perpetrator.
- Health care institutions should be stopped from using specific codes to label HIV-patients or any patients for that matter.
- The current situation where special days and special clinics are designated for HIV/AIDSpatients was found to be discriminatory and should be avoided.

HIV/AIDSpatients like others should be allowed to visit the clinic at any time and should not be isolated in any particular place for treatment.

- There is need for more professional training programmes for nurses, midwives and other categories of workers. There is need for continuous education of health workers for improved attitude towards women diagnosed of HIV/AIDS
- It is important to continue with testing of women during pregnancy for HIV/AIDS but there should be adequate psycho-social support immediately at the point of awareness.
- Women diagnosed with HIV/AIDS should be empowered to fight internal stigmatization wherever it occurs.
- Partners and family members should be educated and counselled on the need for them to accept and support diagnosed family members, rather than discriminating and stigmatizing them as is usually the norm.
- Couples should be tested together; male partners especially should be encouraged to also test for the HIV/AIDS virus and not to blame women for bringing the virus home.
- Community members must be encouraged to accept mothers living with HIV/AIDS and to assist them when they need help. This could be achieved through the formation of community support groups.Health workers at the various health facilities should be aware of the support groups and be in the position to introduce and direct the pregnant women to the groups for support.
- The code of conduct of nursing practice which states that nurses and midwives must respect confidential information obtained in the course of professional practice and refrain from disclosing such information without the consent of the patient, client or relative or legal guardian except where such disclosure is required by law or by order

from a court of jurisdiction or is necessary in the public interest need to be further propagated and enforced.

- The study has implications for the composition of treatment teams for HIV/AIDSpatients in our hospitals and clinics. Given that the patients suffer from multiple challenges, it will be necessary for treatment teams to be multi-disciplined and diverse in nature. The team for HIV/AIDS at the hospital level should include at the minimum a clinical psychologist who should be responsible for the provision of psychotherapy for the patients.

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APPENDIX A

INFORMATION SHEET –UNIVERSITY OF GHANA LEGON

Participant information sheet for a study on: Experiences on pregnant woman diagnosed with HIV/AIDS at Ridge Hospital in Accra Metropolis.

Principal investigator: Mabel Kafui Torku, School of Nursing University of Ghana, Legon.

I am a student pursing a Master of Science (MSc) program in school of Nursing at University of Ghana, Legon. As part of this degree, am undertaking a research work to explore the experiences of pregnant women diagnosed with HIV/AIDS at Ridge Hospital in Accra Metropolis. The University requires that ethical approval be obtained for research involving human participants.

You are kindly invited to take part in this, before you decide, it is important that you understand why the research is being done and what it entails. Feel free to ask any questions which bothers your mind and do not hesitate to ask for the meaning of any word which you don't understand.

The purpose of the study seeks to explore the experiences of pregnant women diagnosed with HIV/AIDS.

The objectives are to find out the copies strategies of pregnant woman diagnosed with HIV/AIDS. And also to explore social support system for pregnant woman diagnosed with HIV/AIDS.

Kindly read the following information carefully and discuss with others if you wish to. You are free to go and think about it and come back later if you wish to do so. You have been asked to participate because, you are a pregnant woman diagnosed with HIV/AIDS, and attending antennal clinic at Ridge Hospital within Accra Metropolis. You will be required to participate in an interview, and give answers to questions and tell me your story in your own words. The interview is expected to last between 45 minutes to 1 hour. You are free to withdraw from the study any time you want, and you will not be affected in any way. Please inform me at the time of your withdrawal. Responses collected will form the basis of this research work and will be put into a written report on an anonymous basis. It will not be possible for you to be identifies personally. Only grouped responses will be presented in this report. All material collected will be kept confidential. No other persons apart from my two supervisors: Dr. P.P Nyaledzigbor and Dr. Daniel Arhinful will listen to the tape. All transcribed interviews will be kept under lock and key for five (5) to seven (7) years in school of nursing and later destroyed when no contradictory issue arise. If you have questions or want further information about the project, please contact me or my supervisor:

Dr. P.P Nyaledzigbor at the School of Nursing,
University of Ghana, Legon
P.O. Box LG 43
Accra, Ghana.

Mabel KafuiTorku
Phone number 0244123810
Signed: ………………………………
Date: ………………………………...

You will be given a copy of the form to keep.

Thank you.

APPENDIX B

CONSENT FORM

Title of Study: Experiences of pregnant women diagnosed with HIV during pregnancy.

This is a document which ensures that you are informed about the research, you have read or it has been explained to you. You have understood it and you are willing to participate in it. I am carrying out a research on the experiences of pregnant woman diagnosed with HIV/AIDS. This means that I will ask you a few questions and you will tell me your story in your own words. I will audio tape your voice, but will not link you to the information by your name. You can therefore sign or thumbprint after every word in the paper has been explained to you. If you find any unfamiliar word, do not hesitate to ask for the meaning.

Possible Risk and Benefits

The researcher does not expect any harm or risk during this research. It only requires the participant to tell her own story as it is. There is also no direct benefit, but this research will help adopt better strategies to manage pregnant women diagnosed with HIV/AIDS in future.

Confidentiality

Any conversation between you and the researcher would be strictly confidential and your own names would not be used. All information would be kept out of reach of public domain.

Contact: If you have any further questions please contact me, Mabel Torku on 0244123810.

Volunteer Agreement

The information describing the benefits and procedures for the research titled experiences of pregnant women diagnosed with HIV/AIDS at Ridge Hospital has been explained to me. I was allowed to ask any question about the research.

I agree to participate as a volunteer

……………………… ………………………………………

Date *Signature /Thumbprint of volunteer*

If volunteers cannot read the form themselves, a witness must sign here.

I was present whilst risk and benefit procedures were explained. All questions answered satisfactorily and volunteer has agreed to take part in the research.

…………………………………… …………………………………………….

Date *Signature of Witness*

I certify that the nature and purpose, the potential benefits and possible risk associated with participating in this research has been explained in this research have been explained to the above individual.

……………………………… ………………………………………….…

Date *Signature of a person who obtained consent*

APPENDIX C

INTERVIEW GUIDE

BACKGROUND INFORMATION

1. Please tell me about yourself

(Probes)

- Age
- Marital status
- Ethnicity
- Occupation
- Religion
- Educational background

2. Please tell me about ANC service

(Probes)

- What are the benefits of Antenatal to you?

3. Please tell me about your experiences with HIV counselling and testing at the ANC

(Probes)

- Were you worried?
- Were you happy?
- Were you glad?
- Or were you relieved?

4. Please tell me your emotional feelings when you were informed about your HIV positive diagnosis

(Probes)

- How did you react to the HIV diagnosis/news?
- What came into your mind after being told the news?
- Whom did you share the news with?
- What are your hopes and fears about being HIV positive?
- What do you think about the pregnancy and the condition?

5. Please tell me / people or significant others reaction to the diagnosis.

(Probes)

- Who are the people you informed about the Diagnosis?
- Tell me your partner's behaviour towards you after you were diagnosed.

6. Psychological Issues; tell me your emotional reaction about your diagnosis

- Were you worried?
- What was your fear?
- What about your ability to engage in work as usual?
- What about your ability to attend social gatherings
- What plans do you have for the care of the baby?
- Others

7. Tell me the attitude of people who know about your diagnosis towards you?

- What is the attitude of health care professional workers towards you?
- Others

8. Tell me your experiences with the ARV in pregnancy.

- What are your plans for the care of the unborn baby?
- What are your plans to breast feed or not to breast feed?

9. Tell me about any social support for you and the unborn baby

(Probes)

- What social support do you get from nurses / doctors, health workers?
- What about financial support?
- What plans do you have for a care taker?
- What support have you received from any NGO?
- What support Health care Professional?

COPING STRATEGIES

10. Tell me how you are coping with this diagnosis

(Probes)

- How are you coping with the pregnancy?
- What about work?

- How are you coping with your daily activities?
- Are you able to do your household chores?
- Is there anything else you want to discuss with me?

11. Is there anything else you will like to discuss with me?

Thank you.

APPENDIX E

SOCIO DEMOGRAPHIC DATA OF PARTICIPANT

Participants Label	***Pseudonym***	***Age***	***Education***	***Marital Statues***	***No. Of Children***	***Gestation of Pregnancy***	***Age Of Current Baby***	***Occupation***	***Religion***	***Place Of Residence***
PA$_1$	Amina	33	No formal Education	Married	1 alive 1 dead	5 Month		Petty trading (sells shoe)	Moslem	John Teye
PB$_1$	Nana	24	SHS Graduate	Married	1st pregnancy	6 months		House wife	Christian	Accra Newtown
PC$_1$	Ajo	36	SHS Graduate	Married	2 children all alive	8 months		House keeper	Christian	Accra James town
PD$_1$	Serwaa	34	JHS	Married	4 children all alive		2 weeks	Petty trading	Christian	Fadaman, Accra
PE$_1$	Afia	36	P 4	Married	4 children		2 weeks	House wife	Christian	Applaku
PF$_1$	Afua	27	JHS	Divorced	-	6 months		Hair dresser	Christian	Ashongman
PG$_1$	Adwoa	32	JHS	Married	1 child alive	6 months		House wife	Christian	Teshie
PH$_1$	Yaa	42	Tertiary	Divorce	1st pregnancy	4		Teacher	Christian	La

				d		months				
PI_1	Ama	28	SHS Graduate	Divorced	1st pregnancy	7 months		Hotel attendant	Christian	Dansoman
PJ_1	Rukia	32	JHS	Married	2 children all alive	5months		Dress maker	Moslem	AbekaLapaz